

Parents' attitudes toward the process of attaining a diagnosis of autism spectrum disorder for their children



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BACKGROUND

- o Parent perspectives often differ from traditional scientific/professional ones and frequently invoke spiritual, moral, or personal interpretations.
- o The understanding of patients' culture, preferences, values, and worldview is an integral part of evidence-based practice
- o Parent's attitudes and responses to having a child diagnosed with ASD will guide their search of professional help and use of services
- O This knowledge is crucial in the design and development of public policies for screening, diagnosis and general access to services.

AIMS

Explore parents' attitudes toward the process of attaining a diagnosis of autism spectrum disorder for their children in a sample of Venezuelan caregivers.

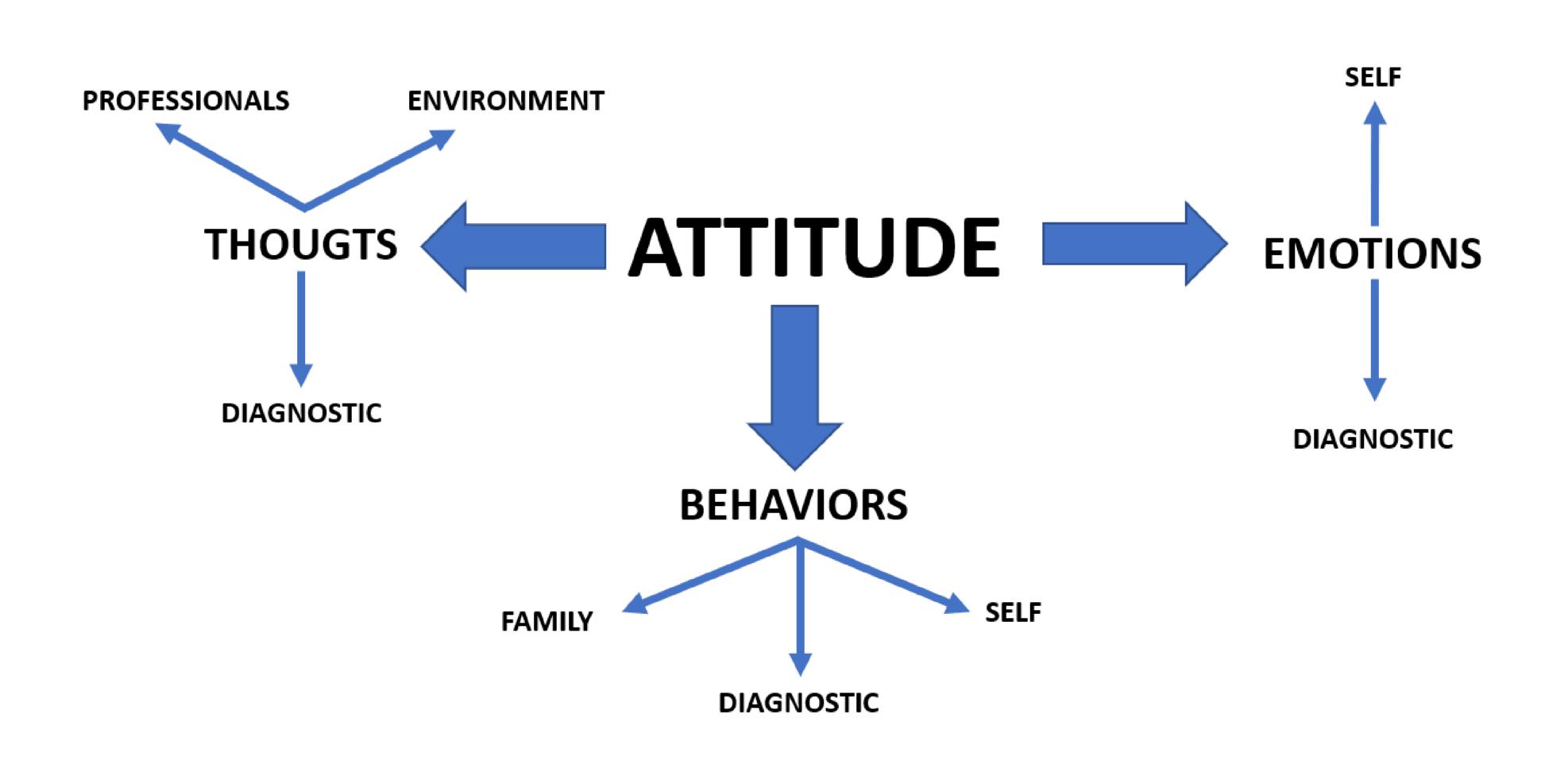
METHODS

- o **Sample:** 20 Venezuelan parents of children between 5 and 10 years of age with a diagnosis of ASD were interviewed. Parents were recruited via key informants at special schools, child development centers, and health clinics.
- o **Primary inclusion criteria**: having a child who was already identified as meeting criteria for ASD. Diagnoses had been given by pediatricians, local clinical psychologists, and special educators using standard DSM-based criteria.
- o **Instrument:** a semi-structured qualitative interview which was validated by experts.
- o Sessions were audio recorded and transcribed. Two researchers coded transcripts, and data were analyzed using thematic analysis (phenomenological approach).
- o The research was embedded in a larger project on ASD in Venezuela

RESULTS

The data was analyzed by deconstructing the Attitude concept into its three components:

- 1) parents' thoughts about diagnostic and the professionals involved in the diagnosis,
- 2) parents' behaviors related to diagnostic, family and self, and
- 3) parents' emotions about diagnostic and self.



THOUGHTS	Future of the child
	Autism as a blessing and a lesson
	Autism diagnosis impacted family union
	Parents relate autism diagnosis with effort, learning, and dedication
	Lack of knowledge about autism
THOUGHTS	Parents relate autism diagnosis with effort, learning, and dedication Lack of knowledge about autism

	Parents sought professional help when they noticed something was
	wrong with their child.
BEHAVIORS	When parents informed the extended family about the diagnostic,
	they received acceptance and support
	Lack of economic means were the first difficult to obtain services.
	Need of more free time to care for their child.
	Knowledge obtained thru the diagnostic process helped them to
	identify their child's behaviors.
	After the diagnosis parents felt sad, surprised, anxious and hopeful.
EMOTIONS	Fear was the primary emotion when they realized something was
	wrong with their child.

Parents identified knowing about their child's autism as something

CONCLUSIONS

- O Parents expressed ambivalent attitudes with both positive and negative thoughts, emotions and behaviors related to acceptance, decision making, searching professional help for the mental health of their children.
- o Themes that emerged:
 - o Concerns about the costs of services, availability of services,
 - o Organization of time,
 - o Concerns about the future of their child
 - o Acceptance and support from extended family
 - O Sadness and Fear as prevailing emotions when confronted with the diagnosis of Autism.

o Their lived experiences about knowing of their child's autism, identify it as a defeat, uncertain and something unfortunate.

unfortunate and as a defeat.

- o Results contribute to understanding how parents' attitudes toward the process of attaining a diagnosis of ASD for their children are related to the availability of services, financial burden, and support from family.
- o Practice implications: improve psychological support f by health care providers to mitigate family stress and isolation.
- o These results have important implications for future work with Hispanic families and supporting them in the process of identification and diagnosis of ASD of one of their members.

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